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‘With this study, we have hope that something is coming’: community members’ perceptions of HIV cure-related research in Durban, South Africa – a qualitative focus group study

Karine Dubé[1,2], Deli Mthimkhulu[3], Wiseman Ngcobo[3], Deborah Mindry[4], Luyanda Maphalala[5], Vanessa Pillay[5], Whitney Tran[1], Ana Korolkova[1], Thumbi Ndung’u[6,7,8,9] and Krista Dong[9,10,11]

[1]Division of Infectious Diseases and Global Public Health (IDGPH), University of California San Diego (UCSD) School of Medicine, La Jolla, CA, USA; [2]University of North Carolina at Chapel Hill Gillings School of Global Public Health, Chapel Hill, NC, USA; [3]Integration of Tuberculosis in Education and Care for HIV/AIDS (ITEACH), Durban, South Africa; [4]Center for Gender and Health Justice, University of California Global Health Institute, Los Angeles, CA, USA; [5]Females Rising through Education, Support and Health (FRESH), Durban, South Africa; [6]HIV Pathogenesis Programme (HPP), The Doris Duke Medical Research Institute, University of KwaZulu-Natal (UKZN), Durban, South Africa; [7]Africa Health Research Institute (AHRI), Durban, South Africa; [8]Division of Infection and Immunity, University College London, London, UK; [9]Ragon Institute of Massachusetts General Hospital (MGH), Massachusetts Institute of Technology (MIT) and Harvard, Cambridge, MA, USA; [10]Massachusetts General Hospital, Boston, MA, USA; [11]Harvard Medical School, Cambridge, MA, USA

Background: Developing a cure for HIV remains a global scientific priority. In 2022, the Females Rising through Education, Support and Health (FRESH) cohort launched an HIV cure-related trial involving an analytical treatment interruption (ATI) in Durban, South Africa.
Objectives: To explore community perspectives about HIV cure-related research.
Methods: Between July–August 2022, we conducted three focus groups with community members. We transcribed audio recordings verbatim and used content analysis to analyze the data.
Results: Twenty community members (13 women and 7 men) participated in three focus groups (HIV status not included). Participants viewed HIV cure-related research as a way to address the issue of defaulting on (not taking) HIV treatment. Participants expressed hesitancy around ATIs, since these contradict longstanding treatment adherence messages. Participants shared concerns around the risk of side effects from experimental interventions balanced against potential efficacy. They advocated for trial participants to have the right to decide whether to inform their sex partners about their HIV status and ATI participation, rather than research teams making disclosure mandatory. Focus group participants also emphasized the importance of using simple language to explain HIV cure-related research.
Conclusions: With HIV cure trials set to launch across Africa in the future, there is a critical need to better understand and respond to local community needs and preferences and to adopt this as standard practice prior to regional trial implementation.

KEYWORDS: HIV cure research, women, analytical treatment interruptions, community perceptions, Sub-Saharan Africa

Introduction

In South Africa, where the greatest number of people living with HIV reside, HIV prevalence among young women aged 18–24 is nearly four times greater than

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Correspondence to: Karine Dubé, Division of Infectious Diseases and Global Public Health (IDGPH), University of California San Diego (UCSD) School of Medicine, 9500 Gilman Drive, MC, 0507, La Jolla, CA, 92093-0507, USA. Email: kdube@health.ucsd.edu

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that among young men.[1–4] The disproportionate HIV acquisition risk for women can be attributed to biological, behavioral, and socio-structural factors.[5] Current HIV prevention approaches aimed at women in the region, such as once-daily oral pre-exposure prophylaxis (PrEP),[6–8] have demonstrated inconsistent effectiveness due to low adherence[9–12] in the presence of social and economic vulnerability. The advancement of effective HIV prevention and treatment options, especially options that are acceptable for young women in sub-Saharan Africa is thus a priority.[13] For those who acquire HIV, antiretroviral therapy (ART), though widely available, carries challenges related to tolerability, adherence, costs, and stigma.[14] Therefore, developing a cure for HIV remains an urgent global scientific priority, particularly in resource-limited settings.[13,15,16]

In 2012, the *Females Rising through Education, Support and Health* (FRESH) cohort was launched in Durban, South Africa,[17,18] and enrolls women aged 18–24 at high risk of acquiring HIV. FRESH participants are enrolled in groups of 25–30 each month to participate in a 9-month longitudinal research study. Intensive HIV prevention counseling and PrEP is provided, with HIV RNA testing performed twice per week to ensure any breakthrough infections are detected and treated with ART immediately. All study participants are co-enrolled in an empowerment program that includes career- and life-skills training, with classes that coincide with the frequent HIV testing schedule. The socio-economic intervention was designed to address challenges facing women living in poverty that contribute to HIV risk, including high drop-out rates from school, intimate partner violence (IPV), economic dependence, and food and housing insecurity. For those who acquire HIV, the same conditions and challenges contribute to low adherence to ART.

To date, FRESH has enrolled 3,043 women and detected 101 acute HIV infections. Immediate HIV treatment limits viral reservoir size and diversity,[19,20] making FRESH acute cohort members ideal candidates for HIV cure-related research interventions. In June 2022, FRESH launched an HIV cure-related trial to assess a regimen of dual broadly neutralizing antibodies (bNAbs) and a toll-like receptor 7 (TLR-7) agonist[21] in early treated virally suppressed individuals. This trial also involves a temporary pausing of ART, called an analytical treatment interruption (ATI), to determine whether the regimen allows recipients to achieve post-intervention control or suppression of HIV in the absence of ART.

The interventional trial implemented at FRESH directly addresses calls to action to bring HIV cure-related research to resource-limited parts of the world.[13,16,22–24] By HIV cure research, we mean any strategy aimed at either eliminating HIV from the body or conferring a state of durable ART-free suppression or control (hereafter referred to as post-intervention control).[25] The HIV cure-related research agenda encompasses several modalities under investigation, such as immune-based approaches, latency reversal or permanent reservoir silencing agents, cell and gene therapies, or combinations.[15] To date, most HIV cure trials have been conducted in the United States and Western Europe, among predominantly male populations limited in racial and ethnic diversity.[25,26] As most HIV cure trials have been aimed at U.S. or European demographics, support strategies for those trials may not translate well to resource-limited contexts. It is imperative for investigators to understand local socio-contextual factors that directly affect recruitment and retention of key populations for whom HIV cure-related trials are ultimately intended.

There is a growing literature that includes community perspectives about HIV cure-related research in Africa. For example, Moodley and colleagues conducted formative work reporting community perceptions of HIV cure-related research near Cape Town, South Africa.[27] Their qualitative interview study revealed limited awareness and understanding of research towards an HIV cure.[27] Another similar study concluded that because HIV prevention, treatment and cure-related research are interrelated, intensified collaborations that include community engagement are needed to shape research agendas.[28] A more recent cross-sectional survey conducted in Ghana among people with HIV (PWH) revealed hesitancies toward inclusion of ATIs used in HIV cure protocols due to concern around risks.[29]

As part of site preparedness activities for the interventional trial implemented at FRESH, we conducted a focus group study to explore the perspectives of community members around HIV cure-related research in the Umlazi area of Durban, South Africa, where the FRESH trial is taking place. Our study aimed to highlight the value of engaging the community when planning HIV cure-related research to ensure acceptability and appropriateness in the local population and setting.[30–32] We also wanted to obtain community input to inform the design of future HIV cure-related intervention trials. The overall goal of this research is to facilitate the translation of our findings[33] to other similar populations who are disproportionately affected by HIV and have the most to gain from an effective HIV cure-related intervention.

Methods

Study setting and participants

From July–August 2022, we conducted focus group discussions (FGDs) at the FRESH clinical research site, located in the Umlazi township near Durban, South Africa. We chose FGDs because these are ideal for bringing out perceptions and attitudes.[34] FGDs are also suitable for assessing community-level understanding and exploring how participants ascribe meaning to various topics.[34,35]

Recruitment

Participants were recruited from members of local community advisory boards (CABs) and by referral from CAB members, using a convenience sampling methodology. Recruitment was not based on HIV status, but on being able to represent the local community concerns related to HIV care and research. In advance of each FGD, participants were provided with a fact sheet describing the FRESH cohort, the protocol for the interventional HIV cure-related trial, and the socio-behavioral component of the study. Eligible participants were at least 18 years old, able to provide written informed consent, and reside in one of the local communities in or surrounding the Umlazi township where the FRESH HIV cure-related interventional trial is being conducted.

Table 1. IRB-Approved focus group guide – community members' perceptions of HIV cure-related (post-intervention control) research (Durban, South Africa, 2022).

Introduction and Prior Community Involvement

- How long have you been involved as a community member? What types of studies or trials did you advise on?

Perceptions of HIV Cure-Related (Post-Intervention Control) Research

- What are your thoughts about the FRESH program?
- What are your thoughts about the importance of including young women in 'HIV cure' research or studies aimed at post-intervention control?
- What is your understanding of 'HIV cure research' or research aimed at post-intervention control of HIV? What are your thoughts about the proposed HIV cure-related interventional trial?
- What is your understanding of why 'analytic treatment interruptions' (ATIs) or pausing ARV drugs are included in trials aimed at post-intervention control? OR How do you feel about research involving ATIs (pausing ARV drugs)?
- Do you have any concerns about "HIV cure" research or studies aimed at post-intervention control? If yes, what are they?

Disclosure and Partner Protection Measures

- How would you address the tendency for young women to avoid disclosing their HIV status and participation in studies with ATIs (pausing ARV drugs) to their sex partners?

Community Engagement Considerations

- What terminology/language should be used to describe 'HIV cure' research and studies on post-intervention control? Is there any terminology/language that would be problematic?
- Do you think community members should be informed about "HIV cure" research or studies aimed at post-intervention control? If yes, why? How? Which members of the community should be informed?

Additional Information

- Do you have any additional recommendations for 'HIV cure' research and studies on post-intervention control?

Data collection

Three FGDs were conducted in a private conference room at the FRESH site. Following informed consent, participants completed a brief demographic questionnaire. A trained facilitator (DMt) conducted the FGDs, ensuring all participants' voices were heard. Discussions took place in English and, depending on participants' preferences, in the local language, isiZulu. FGDs were audio recorded and lasted between 60–90 min. Following each FGD, participants received 150 South African rands (approximately $9.00 USD) and lunch.

The facilitator followed the IRB-approved FGD guide (Table 1), developed in collaboration with members of the HIV Pathogenesis Programme (HPP) community advisory board (CAB) who are familiar with the FRESH clinical research program. The guide contained questions in English and isiZulu, and covered topics including: (1) prior community involvement, (2) perceptions of HIV cure-related (post-intervention control) research – including perceptions of the FRESH program, thoughts about the importance of including young women, understanding of HIV cure-related research, understanding and perceptions of ATIs, and concerns about HIV cure-related research, (3) disclosure and partner protections considerations in the context of an ATI, and (4) considerations for community engagement.

Data analysis

Audio recordings of isiZulu and English were transcribed verbatim by a study team member (WN) who removed all potential identifiers. The transcript was translated to English by a second study team member. To analyze the qualitative data, we used a combination of conventional content analysis, combined with a modified grounded theory approach (assessing how participants construct meaning and knowledge).[36–38] Transcripts were read through multiple times, informing the creation of a preliminary codebook that contained code names, brief descriptors, and examples. A social scientist (DMi) coded the data using an open coding method and a second social scientist (KD) reviewed and edited the codes. The codes were reviewed and discussed with members of the FRESH research team during team meetings. Salient text units were identified, codes ascribed, and the resultant codes were organized into a narrative.[38] Discrepancies were resolved *via* discussion and consensus. A combination

Table 2. Demographic characteristics of focus group participants* (Durban, South Africa, 2023).

Focus Group Number – Participant Identification	Sex Assigned at Birth	Age (years)	Affiliation	Familiarity with Post-Intervention Research Trial
Focus Group 1 – Participant 1	Male	56	Local Community Advisory Board	General understanding
Focus Group 1 – Participant 2	Female	36	Local Community Advisory Board	General understanding
Focus Group 1 – Participant 3	Female	24	FRESH Graduate	Very limited
Focus Group 1 – Participant 4	Male	59	Local Community Advisory Board	A little familiar
Focus Group 1 – Participant 5	Female	48	Referred by Community Advisory Board Member	Very limited
Focus Group 1 – Participant 6	Male	51	Local Community Advisory Board	Very familiar
Focus Group 2 – Participant 7	Female	39	Community Member near FRESH	Very familiar
Focus Group 2 – Participant 8	Male	37	Local Community Advisory Board	Very limited
Focus Group 2 – Participant 9	Male	52	Local Community Advisory Board	Very familiar
Focus Group 2 – Participant 10	Female	46	Local Community Advisory Board	Very familiar
Focus Group 2 – Participant 11	Female	54	Local Community Advisory Board	A little familiar
Focus Group 2 – Participant 12	Female	34	Local Community Advisory Board	Very limited
Focus Group 2 – Participant 13	Male	39	Not applicable	Very familiar
Focus Group 3 – Participant 14	Female	28	Referred by Community Advisory Board Member	A little familiar
Focus Group 3 – Participant 15	Male	31	Referred by Community Advisory Board Member	A little familiar
Focus Group 3 – Participant 16	Female	44	Referred by Community Advisory Board Member	Very limited
Focus Group 3 – Participant 17	Female	39	Local Community Advisory Board	Very familiar
Focus Group 3 – Participant 18	Female	37	Referred by Community Advisory Board Member	A little familiar
Focus Group 3 – Participant 19	Female	22	Referred by Community Advisory Board Member	Very familiar
Focus Group 3 – Participant 20	Female	49	Local Community Advisory Board	Very familiar

*All participants were Black Africans.

of Atlas.ti (version 23, Berlin Germany) and manual coding was used to support data management and analysis.

Ethics statement

The IRB of record was the University of KwaZulu-Natal (UKZN) Biomedical Research Ethics Committee (BREC) (#00002897/2021). In addition, the Mass General Brigham (MGB) IRB (protocol #2022P000729), University of North Carolina at Chapel Hill IRB (protocol #22-0473) and the University of California San Diego IRB (#806466) reviewed the study.

Results

Twenty individuals, 7 male and 13 female, aged 23–60 years (median 39 years) participated in three FGDs. Participants provided their general perspectives on HIV cure-related research and gave specific input about the HIV cure-related interventional trial being conducted at FRESH (Table 2). Participants ranked their baseline knowledge of HIV cure-related research as follows: very familiar (n = 8), general understanding (n = 2), a little familiar (n = 5), and very limited knowledge (n = 5). Focus groups were mixed with respect to prior familiarity to HIV cure-related research.

Prior community involvement

Participants served on various local CABs, including the HIV Pathogenesis Programme (HPP) who advise on the FRESH study, and other key research and advocacy organizations serving in the greater Durban area. At least a third had served on CABs that advise on research studies, and most had served on CABs for over 10 years. The majority of participants were very familiar with the FRESH program.

One-third of participants reported experience with HIV prevention and treatment services, a fifth reported experience working in health care settings (including HIV counseling), and a sixth reported experience with childhood development and education. One community member was a prior FRESH cohort participant. Participants also shared their lived experiences during the FGDs. For example, one participant was proud to be in an HIV sero-different relationship.

A few participants had been involved in HIV-related activism and recounted the early days of the HIV/AIDS epidemic in South Africa prior to the availability of life-saving ART. These memories, including having friends and family who died without treatment, fueled their involvement in HIV-related interventions.

Perceptions about the FRESH program

Overall, community members held positive views about FRESH, with the main reasons centering around the provision of empowerment and life skills to young women, as well as hard skills, such as computer knowledge. Community members valued that FRESH focused on women's health and HIV prevention. They perceived that FRESH was reducing the effects of social ills on young women.

> *When I came here, to FRESH, all I wanted was the computer course, that was the only thing that I saw as missing. [But] when you are inside the doors you see that there is more than just computer[s]. There is health here, we talk about the life of a woman… We spoke a lot about women's health, we spoke about uplifting each other, if you are a woman who is looking down upon other women nothing will be alright, we need each other, holding each other's hand so that life may continue.* – Focus Group 1, Participant #03

Community members emphasized the importance of making parents of participants aware of the FRESH program, noting that FRESH not only offers direct support to the young women, but also offers their parents indirect support.

Perceived importance of including young women in HIV-related research

Participants commented on the importance of including young women in HIV prevention and HIV cure-related research. One community member described how young women, while still school-aged, engage in relationships out of economic necessity, exchanging sex with older men to cover basic needs (e.g. food) or to afford luxury goods (e.g. cell phones). Participants noted that supporting young women to become financially independent as is done at FRESH helps address these challenges.

Participants noted that young women require support to initiate positive change in their lives. FRESH was perceived as a champion of women's health and rights. A participant touched on the importance of protecting women for future generations.

> *I do not understand why, because by the time I say, "Mom, I am HIV positive", my mother won't say what she has to say to me, she will just say, "Life goes on my child" and we continue with life… So, if I find the real support group, maybe I will change the behaviour. Now I am living a different life… I really support the initiative of taking these young women… If we lose females, I do not even like to think of what will be the way forward.* – Focus Group 1, Participant #03

Participants valued having a research program centering on young women in Durban, South Africa. They perceived young women to be more willing to visit HIV clinics than men.

> *It is good that this study is brought here in South Africa in a centre that deals with youth and especially females as they are the ones who are regular clinic attendees and open about HIV compared to males who wait for the red carpet for them to go to [the] clinic… [all participants laughing].* – Focus Group 2, Participant #11

Participants also expressed a desire to see a similar initiative for young men in the community.

> *Why not for the young men as well? We wish the researchers would open this avenue. Maybe in a small pilot? … Before a woman takes her pants off, there is someone who first opens their zip, someone that is a male. In this case the man, there are men who open their zip and find out that they are older than them… That is a concern… they should also consider young men, how they can be approached. Knowing very well that there is what we call Isibaya Samadoda [Men's Support Group], but this grouping has the cultural approach which is to educate the man on how he should behave as a man. But in research as well, we should teach the men what they should know about the research.* – Focus Group 1, Participant #06

Perceptions of HIV cure-related research

When asked to share their understanding and perceptions of HIV cure, some participants expressed the view that early treatment combined with a cure-related intervention could lead to a future without HIV.

> *In my perspective, as they say it's a cure, it will be a cure because if you take a person on ARVs [antiretrovirals] at an early stage, which means that the real virus has not yet spread in that person, if there is a second intervention, which means that the power of killing the virus as such will now be a little stronger, and then there will be a new nation which will be created that will be HIV negative.* – Focus Group 1, Participant #01

A number of participants discussed the challenge of HIV-stigma in the community. They expressed concerns about HIV-related stigma in the community as a barrier to disclosing HIV status.

> *Because in the community they laugh at each other, and you don't know what makes these people laugh, because the person has said that he is positive. But this person who said that he is positive, or disclosed his status, and the way he lives. Then you who don't know [your HIV status], ask yourself if this person is right in the head, why are they saying that they are positive.* – Focus Group 1, Participant #05

One participant described the draw of joining HIV cure-related research and how a cure could help reduce the incidence of rape of virgins to get rid of the virus – a once common belief in some parts of South Africa.

> *A person will say I am going to test as I want to take ARVs, I also want to join this research to get rid of HIV. To get rid of the thinking of going around raping young people because they want to eliminate HIV, doing away with that thought and finish all those things that to finish HIV you have to sleep with a young person* [virgin]. – Focus Group 1, Participant #05

Some community members viewed an HIV cure or long-acting intervention as a necessity to eliminate the high cost of daily HIV treatments. They expressed concern about the country's ability to continue providing long-term access to ART in the context of an economic downturn; while South Africa currently covers HIV medications for all people with HIV, it may not afford to do so in the future.

> *It will help us if you look at the South African economy. With what is happening right now, we will end up not getting even these ARVs. If you look at the situation we are in, therefore getting something that you will take once, and it stays in your blood for longer period. So, I am looking at it now economically, as a person who is close to employment issues. So now… it will show us that even if the South African economy is hitting us, having no food, but [this intervention] in the blood, I will still have it protecting me… I accept this with both hands, it will be of great help to the people of South Africa.* – Focus Group 1, Participant #04

Participants emphasized the importance of being optimistic about the success of HIV cure-related research, despite the associated risks and potential for failure, emphasizing the magnitude of benefit and relief that a cure would provide to individuals who have been on daily treatment for years.

> *It is a win-win situation, as studies are there to find a breakthrough, you see as much as it is scary, as people we can have doubts on what if it doesn't work, we mostly focus on a negative part of what if it doesn't, instead of what if it works and how many people who are on treatment will benefit, especially there are people who have been on ARVs for more than 20 years or 30 years who really need this break, so yah it will be a breakthrough.* – Focus Group 3, Participant #16

> *Yes, I appreciate and would be happy if there can be another way which can help in taking of pills, the way which will make it possible for us to pause taking our pills or just stop permanently. So, with this study we have hope that something is coming.* – Focus Group 2, Participant #12

One FDG participant shared a detailed understanding of how bNAbs work inside the body and overcome HIV hiding in reservoirs.

> *From what I heard… HIV goes into hiding in the reservoirs, brain, spleen and lymph nodes, these bNAbs will go and do something called, I forgot what it is called, maybe it [the virus] will come back, they [the drugs] go there and trigger, and then it [the virus] comes out and when it comes out, it goes back into the blood stream, and then the bNAbs are able to attack it. Because bNAbs are protein in nature, they are amino acids, they will cover and attack the virus. If it happens that the bNAbs are here to attack the virus, which means you will never continue with your ARVs, that is right.* – Focus Group 1, Participant #01

Another participant expressed support for the HIV cure trials, while emphasizing the critical importance of ensuring participants are fully informed about every aspect of the research including how they will be monitored. Others asked questions about the trial, such as the age limit, duration, study, and monitoring procedures.

> *I can say that this research is good and it will work well but what is most important is that those participating must be fully briefed in the right way, they must know how it works, what is required of them. We conduct research to see if something is working or not. It is not that they are told to stop taking their ARVs just for the sake of stopping, but in order to see if bNAbs will work or not. They should know that every time they will be monitored, being watched for everything that will happen to them, and what should be encouraged to them is to come to FRESH whenever they see changes, it doesn't matter how small is the change they see in their bodies, and ask FRESH staff.* – Focus Group 2, Participant #09

Participants viewed the interventional trial as a means of addressing rising ART default (not taking HIV treatment), with one expressing fear that ongoing default could bring back the country's pre-ART death rates. One discussed how people do not like taking their pills daily and that an HIV cure could even reduce the use of toxic street drugs.

> *It will be good for us to be positive in the fact that the study will be starting and it will assist in that we don't find people defaulting because if we can look right now the number who are no longer going to iThembalabantu to collect their ARVs. You will see that there is a huge problem which is there in the community which one day we will see ourselves going back to that year 2000 where we were burying day and night, day and night, finding that on a single day you observe 6 funerals in one area. Just because [people with HIV] have defaulted, [and] the disease will do as it pleases in their lives.* – Focus Group 1, Participant #04

> *We all take chances in so many things which are more risky than HIV, I see this study as a good thing since many people are defaulting and others do not like drinking pills. Others even use milk to drink them and others crush them, so there are so many benefits. So it will bring down the level of whoonga consumption [toxic street drug that is a mix of b-grade heroin, rat poison and other chemicals that is which is usually smoked] so there will be so many benefits.* – Focus Group 3, Participant #16

Perceptions of analytical treatment interruptions

One participant described their understanding of a need for taking a 'drug holiday' while on ART, drawing a parallel with ATI, in order to mitigate toxicity resulting from long-term ART use. They believed that promoting ATIs as a means of detoxing from ARTs would reflect favorably on ATI-trials.

> *[A] drug holiday, even the liver itself, it somehow needs to detox because it carries a lot of toxins, which comes from ARVs. I think that if you tell that to a person, explaining it, they will be able to understand. But you have to be more scientific, that as they*

> *are stopping [ARVs], they should understand why. You have to include this concept of detoxing. Because they went on to say if you have been taking them [ARVs] for a long time, the side effects can just sit on your liver. So, I think here people will be excited about this. If you can remember that knowledge is very powerful… then you are able to succeed. Maybe give clarity to people in a way that they will understand, and can see that we are getting helped.* – Focus Group 1, Participant #01

Community members also described the possible negative effects of ATIs. They considered ATIs to be associated with risks and uncertainty, such as HIV returning in full force. They wondered about the development of HIV resistance, and if ATI participants could resume the same ART regimen after interrupting treatment.

> *[We] believe that it is something good but scary at the same time. It is scary because when you tell people to stop taking their ARVs, as people who have knowledge, we know that the virus is hiding when you are taking your ARVs, but once you stop and use the bNAbs, the virus will come out in full force and we do not know what will happen during that time. Even if we are going to be using something else instead, but we are still not sure if that something will work and bNAbs will be able to reach all the places where the virus is hiding.* – Focus Group 2, Participant #07

Some participants noted that there may be hesitancy to accept ATIs, since stopping ART contradicts longstanding treatment adherence messages.

> *They come and encourage us, encourage us for all these years to go and test, busy with testing, test, test going up and down… persuading people to test. And it changes to test and treat. Now when we test you, you get your ARVs… You now say, let us stop, after we have been taking them [ARVs] for long time, what are you saying exactly, to stop now? And see if the virus will rise? … You are saying we must stop now? If we had stopped and the virus rises, you will get pills to be able to treat again. But how sure are you, of that?* – Focus Group 1, Participant #06

Participants emphasized the need to explain why ATIs are needed to advance HIV cure-related research. For example, they suggested that scientists explain that stopping treatment will show whether the immune system can control the virus on its own. They also noted the necessity of preparing trial participants for ART uptake and pause.

Concerns about HIV cure-related research

Participants voiced concerns about the possible compounding of side effects from ART use, when adding experimental interventions (e.g. bNAbs), and asked about the kind of support trial participants would be given when that occurs.

> *But now to counteract the side effects which will happen, because you shouldn't forget that ARVs are already present [in the body], these bNAbs we do not know their side effects, if it is now double side effects, double body toxic, we don't know what will happen there. So, we would like to know when it comes to that stage how will the young people be assisted?* – Focus Group 1, Participant #01

Participants warned of the dangers of trusting anecdotal stories about the benefit of an HIV intervention without a full understanding, as this can cause serious harm or death, underlying the need for full disclosure of risks and benefits when assessing a new HIV intervention.

> *We are living in the world where a person would first like to know if it worked for someone else, will it work for me? Which means if it worked for someone will it also work for me? … I will take a true story from one of the people I know who passed away because someone used some sort of concoction which worked. Here this person is alive and walking has nothing [not sick], not knowing that this someone was using something on the side called immune boosters, which means that someone was taking immune boosters and never told this person to use both [immune boosters and ARVs]. And this person chose to use boosters and ended up defaulting and passed on. So, people will think that they are being told to default now.* – Focus Group 1, Participant #03

A participant explained that there might be confusion for some between having an undetectable viral load with HIV remaining in reservoirs versus not having HIV. If someone believes that they do not have HIV, this confusion would make it difficult to understand the risks of viral rebound during an ATI.

> *In studies we participate voluntarily and for your own protection the participant signs an informed consent to say that they are willing to take a risk, so the risk we are having here is that now the virus has come out of the reservoirs, if they started in 2012 some of them will think they were undetectable… Yes, so if they are undetectable they now see themselves as negative, even though they are not supposed to think that way, right?* – Focus Group 3, Participant #16

Moreover, participants perceived a tension between maintaining confidentiality of the trial and ensuring parents were being informed about the research. They noted that young people rarely disclose their participation in research to their parents and suggested writing a letter informing parents without including sensitive details.

Further, participants mentioned the risk of misinformation about trials in the community. They stressed that providing clear information around acute infection and ATIs is essential to avoid negative perceptions and even protests against the clinical research site. One described misinformation about ATIs attracting people who are drawn by a desire to stop ART. Another explained that participation requirements will have to be clearly explained.

> *I have this one concern, we know that this youth is very sexually active, some of them come here still hiding pills from their families having heard from friends that there is something happening here at FRESH. A friend will then want to join since she has heard that you stop taking ARVs… That they should be really thoughtful about communication as you will end up having queuing outside also wanting to stop ARVs because really people are tired of taking ARVs.* – Focus Group 2, Participant #11

> *To me, the biggest threat is the way people think and the way they are going to receive the information. Because if you take bNAbs there is no threat, if we can remember that these young people start treatment when they are still in an acute stage when the virus has not made any copies in the reservoirs for you to test positive, if let's say she tests positive on Thursday it is either the following day or the same day she is started on treatment. So, it is very important that the way we explain to people is very clear and accurate because that will be of great help in preventing a situation where someone will come and claim that young people are started on treatment and stopped again which will lead to people protesting.* – Focus Group 2, Participant #09

Disclosure and partner protection measures

When asked about HIV disclosure to partners during ATIs, participants noted that disclosure can be difficult for young women with HIV and recommended that research teams provide disclosure support during an ATI trial. Indeed, the third focus group reached consensus that ATI participants should decide whether to inform their partner(s) and that disclosure should not be made mandatory. The group indicated that additional support must be provided for ATI participants who are at risk of IPV from their partners.

> *It is through educating them [young women] about why it is so important to disclose, where is it going to help them. So if they decide not to disclose at the end of the day it will be their choice as we can't force them.* – Focus Group 3, Participant #15

> *Yes, because where I see the danger… when I have an abusive partner who just comes and demands that we have sex and then… he gets infected… It is true that we change partners and we are failing to disclose but we can't be forced to disclose. But since now it involves social workers and psychologists it will really help people to see what happens if I am hiding my status.* – Focus Group 3, Participant #17

Participants underscored the importance of providing HIV prevention support (e.g. PrEP) for sex partners, noting that there should be enough time for PrEP to become effective in the body before having sex. One participant explained the importance of providing information to parents and partners of participants, as they will be supporting the participants during the trial. They also underscored that trial participants are frontline spokespersons for HIV cure-related research in the community, and as such, they must be armed with accurate information sourced directly from the research site.

> *Another thing that is important is that people who are close to [the] study participants, such as parents and partners should be called in and this information explained to them, most importantly to be able to protect themselves, could they be using contraceptives to prevent pregnancy, promote condom usage or encourage their partners to take PrEP. These people are the ambassadors of this study, they are not expected to have knowledge about the study as this will portray another picture to me as a community member, so the correct information should be given to them at all times and not for them to rely on Google as it can have wrong information. Their centre of information should always be FRESH even if there is something they don't understand before going to the clinic they should phone FRESH first so that proper follow up can be possible.* – Focus Group 2, Participant #09

Community engagement considerations

When exploring community engagement around HIV cure-related research being conducted in Durban, South Africa, participants converged on the importance of raising community awareness and were enthusiastic about leading the effort. Participants emphasized the importance of keeping the community informed during trial implementation, and doing so in the local language, and in partnership with the investigators.

> *From the community side… let us promote community outreach, to go and speak to people and say 1, 2 and 3 and what led to 4 and 5. We started here and now we are here. Let's give feedback to the community by all means necessary, go to the community together with the researchers. And while they talk in English, we on our side try with our Zulu.* – Focus Group 1, Participant #06

Participants emphasized the need for clear and simple language easily understandable by the local community. Specifically, language should be adapted to context, which leaves no place for use of scientific jargon and unfamiliar abbreviations.

> *I think that in terms of terminology or language, it depends on where you are, if it is going to be in Umlazi, it means that we will be speaking terminology that is always used on the street because we are the people from the community and the people we will be talking to are from the same community, but it should be someone who understands how we talk outside with people when compared to us speaking here as we are formal. In short it depends on where you are, Amen.* – Focus Group 2, Participant #14

A participant suggested that trusted members of the community should be engaged in the process of disseminating information about HIV cure-related research.

> *I think that as you know that it is not easy to take information down to the community, but since we have people who work in organizations, activists as human guard defenders it will be easy if you start with those people and then they are the ones who*

> *will go to the community and pass the information because the community knows and trusts them, [versus] just having someone coming from outside.* – Focus Group 3, Participant #20

Some participants suggested that the media (e.g. public radio) could be a good way to inform the community, as well as parents/guardians, about HIV cure-related studies. However, another community member believed that it was too early to inform the community at large given the risk of distortion of messages, and to keep the discussion within selected smaller groups.

> *Let me just differ, I will request that we do not inform the community at this stage, because what if it goes wrong? It is better to stick with one small group at first, so that if anything goes wrong it can be easy to manage… Yes, hold it for now, because at the end the information that will be given to people will be wrong, as people will add their things and this ends up in misinformation.* – Focus Group 3, Participant #17

Overall, participants were thankful that research towards an HIV cure was happening in Durban, South Africa.

Supplementary Table 1 provides additional quotes from community members.

Discussion

Our study advances the socio-behavioral sciences literature by providing formative data on perceptions of HIV cure-related research in Durban, South Africa, a region with expertise in HIV prevention and treatment research. Additionally, our study aligns with a recent urgent call to action to integrate social context into global HIV cure-related research.[39] Our qualitative focus group study revealed that community members were optimistic about HIV cure-related research and excited about the possibility of eliminating the need for daily ART. HIV cure was perceived as a means of addressing ART default and HIV-related stigma associated with daily treatment. Concerns were expressed about possible unknown side effects from the experimental interventions, including drug-drug interactions and compounding toxicity with underlying ART use. Mixed feelings were conveyed about ATIs and their associated risks, with emphases on ensuring participants fully understand ATI-associated risks and making PrEP accessible to sex partners. Some raised concerns about requiring disclosure of HIV status and ATI participation, citing the danger of IPV for women. Community members agreed that participants should decide whether to inform their partner(s) and not be required to disclose HIV status in the context of ATI trials. Articulating the goals of HIV cure-related research was deemed especially important.

Community members in our study shared their perspectives about the FRESH study,[17,18] in regard to combining basic sciences with a socio-economic intervention, along the arc of HIV prevention, early treatment and HIV cure interventional clinical trial. The FRESH approach demonstrates the potential for synergies along the continuum of HIV research, described by Moodley and colleagues.[28] Our study sample emphasized the importance of engaging young women in HIV cure-related research and providing adequate prevention support to mitigate the risk of acquiring and transmitting HIV. Community perspectives echoed a recent commentary urging policy makers and researchers to place women at the center of the global HIV response as a core component of reaching global epidemic control.[40] Further, to promote enrollment equity by sex and gender, trial designs will need to center on the lived experiences of women, particularly in areas with the highest burden of HIV. Whereas U.S.-based HIV cure-related trials have mostly enrolled older White men,[25,26] young women will be at the forefront of advancements in novel HIV therapeutics in sub-Saharan Africa in years to come. For this reason, it will be important to design clinical trials that focus on both biomedical and psychosocial needs. Interestingly, community members expressed a desire for similar HIV and life skill programs focused on young men. In light of local socio-economic realities, to further reduce HIV incidence in the region, HIV prevention and treatment initiatives will need to be intensified for both women and men.[10,41]

Participants equated HIV cure to no longer having to take HIV medications and viewed the FRESH HIV cure interventional trial as an opportunity to address HIV treatment default. This finding corroborates a similar one by Moodley and colleagues in Cape Town, South Africa, where stakeholders perceived HIV cure as a return to normality with no need to take medications.[27] In that study, however, healthcare workers viewed HIV cure as complete elimination of HIV from the body.[27] The notion of cure as eliminating HIV from the body was similarly reflected in a focus group study in the United States[42] and qualitative research in Australia.[43,44] Our sample seems more accepting of ART-free durable control as possible goal of HIV cure-related research. In retrospect, the topic of HIV cure-related research as helping address HIV stigma was under-explored in our study. Prior socio-behavioral research showed that HIV cure-related research could have mixed effects on HIV stigma.[45,46] We have found HIV stigma to remain pervasive and a major obstacle to HIV disclosure. The topic of stigma as it relates to HIV cure-related research will require further inquiry in our setting. Another theme under-explored in our current study was the relationship with traditional healers and alternative forms of cure. In a study by Moodley and colleagues, participants invoked the use of local herbal remedies by traditional healers in South Africa.[28] Notably, the view that HIV cure-related research could help reduce incidence of rape was a poignant one and grounded in socio-cultural context, although we believe this view has become less prevalent in recent years. The prospect that an HIV cure could have long-term economic benefits is largely reflective of the costs involved with ensuring access to ART for 2.5 million PWH in South Africa.[47,48]

Moreover, our study revealed mixed feelings around interrupting HIV treatment, mainly because ATIs could be perceived as contradicting longstanding messages around the necessity of strict ART adherence. This apparent contradiction was noted in prior socio-behavioral research in South Africa, Australia, and the United States.[28,43,44,49,50] In another study by Moodley and colleagues, PWH expressed willingness to participate in ATIs only if cure achievement was a guarantee.[27] Similarly, Bonney and colleagues found that 67% ($n = 251$) of PWH would decline ART interruption as part of HIV cure-related research in Ghana.[29] In a study conducted in Thailand among 408 PWH, socio-behavioral scientists found a higher willingness to participate in short-term ATIs (lasting a few weeks) compared with extended ATIs (lasting a few months).[51] A critical recommendation emerging from our study is the need to clearly explain why ATIs are needed to participants and to the broader community, and to make clear that ATIs are conducted in the context of research, not regular care. Consequently, we recommend being careful with the concept of 'drug holiday'. Moving forward, acknowledging local contexts when implementing ATIs will also be an urgent imperative.

Besides possible side effects of experimental interventions, the main concern about HIV cure-related research was the risk of transmitting HIV to sex partners during ATIs. This concern was also reflected in prior socio-behavioral research in a variety of settings.[43,44,50,52] Participants in our study emphasized having adequate information and HIV prevention resources (e.g. PrEP) for sex partners, reflecting a growing literature focused on the need for robust partner protections during ATIs.[53–55] Further, there is increased appreciation that partner protection measures will need to be adapted to local contexts and available resources.[54,55] In Durban, South Africa, HIV cure-related research is being conducted as PrEP is rolled out beyond pilot implementation projects, making provision of PrEP to partners of ATI participants more feasible.

A major finding from our study was the recommendation to not require disclosure of HIV for ATI trial participants, consistent with a similar recommendation to not mandate disclosure of microbicide gel use as part of an HIV prevention trial in Durban, South Africa.[56] Participants in our study emphasized the need to pay close attention to gender and power dynamics and differentials,[55,57] to balance risks for both participants and their partners. In the FRESH cohort, women who acquire HIV receive intensive counseling on partner disclosure and have the option to refer partners for HIV testing and counseling.[58] Nonetheless, additional disclosure support will be necessary for young women who undergo ATIs, as the implications for disclosing HIV (and risks during ATI) may have unforeseen social impacts. It is important to appreciate relationship dynamics as potential barriers to HIV disclosure through the lens of socio-cultural gender inequalities.[56,59] More socio-behavioral research will be necessary around HIV disclosure in the context of ATIs trials in a variety of settings, and not including this research alongside ongoing biomedical trials would be a missed opportunity. In the FRESH cohort, several participants experienced some form of IPV, reflecting the high national prevalence of IPV among young women – estimated at one-third.[60–62] The intersection of gender inequalities, disclosure, and IPV underscores the need for trauma-informed research paradigms[63] when implementing HIV cure trials with ATIs for potentially vulnerable women.

Lastly, participants recommended using simple language to engage communities around complex HIV cure-related research. The divergence of opinions on whether to engage the community at large about HIV cure-related research and ATIs was noteworthy and indicates that research teams will need to be very intentional with defining the level of engagement necessary to support early-phase HIV cure-related trials in Africa. Mitigating risks of misinformation about HIV cure-related research will also be essential. Given the plans for new HIV cure-related trials in Sub-Saharan Africa, substantial investment towards community and stakeholder engagement, socio-behavioral sciences, and ethics research on the continent is essential.

Table 3 provides a summary of community members' considerations for implementing HIV cure-related research in Durban, South Africa.

Table 3. Summary of community members' considerations for implementing HIV cure-related (post-intervention control) research in Durban, South Africa.

- It is important to emphasize the long-term view of research towards an HIV cure. Until a cure for HIV is found, it will be imperative to intensify efforts to prevent and treat HIV for all affected populations.
- Young women will likely be at the forefront of advancements in novel HIV therapeutics in sub-Saharan Africa in years to come. It will be important to design clinical trials that focus on both their biomedical and psychosocial needs.
- There should be clear information about clinical trials available to potential participants and community members.
- Informed consent should be robust. There should be clear information about the experimental intervention, and why ATIs are needed.
- Research teams should clearly explain why ATIs are needed with participants and the broader community. There should be a clear demarcation between HIV treatment (standard of care) and research towards an HIV cure involving ATIs. Research teams should be careful with the concept of 'drug holiday'. Participants should be informed when to stop ART and resume ART in the context of a cure-related study. Acknowledging local contexts when implementing ATIs is an urgent necessity.
- Research teams should provide disclosure support to ATI participants. There was consensus that disclosure should not be mandatory in the context of ATI trials, but strongly encouraged. Relationship dynamics and gender inequalities as potential barriers to HIV disclosure should be appreciated in local socio-cultural contexts. More research will be necessary around HIV disclosure in the context of HIV cure trials with ATIs.
- HIV prevention support (e.g. PrEP) should be offered to sex partners of ATI trial participants. Enough time should elapse for PrEP to become effective in the body before having sex. HIV prevention information to protect partners during an ATI should come from a trusted source.
- There should be additional support to ATI trial participants who may face intimate partner violence.
- When explaining HIV cure-related research in the community, language should remain simple, without scientific jargon or abbreviations, and adapted to contexts. Mitigating risks of misinformation about complex HIV cure-related research will be critical. It is preferable if trusted members of the community share information about HIV cure-related research.
- There will also need to be substantial investments towards community and stakeholder engagement, socio-behavioral sciences, and ethics research in Africa.

Limitations

We acknowledge study limitations. Due to the small sample size, our results may have been thinner on some topics, and we were unable to examine differences in the data by age, sex assigned at birth and prior familiarity with HIV cure-related research. We did not collect HIV status from participants. Further, due to the qualitative nature of this study, we did not quantify the number of participants who responded in certain ways. The hallmark of qualitative focus group research is particularity, not generalizability. Another challenge inherent to the focus group methodology is keeping participants focused on the questions asked, rather than discussing tangential topics. The facilitator tried to mitigate this challenge by refocusing the groups using questions from the guide. Most participants were familiar with the cohort study, which may have influenced responses. Some focus group participants also knew each other prior to conducting the focus groups, which may have influenced group dynamics. Further, we leave open the possibility that we did not achieve saturation[64] of themes in our FGDs. Our study did not include local traditional healers,[65,66] an important population to engage in future socio-behavioral research. Our study under-examined considerations specific to people diagnosed during acute HIV infection,[67] such as the possibility of HIV seroconversions during ATIs for people treated during acute HIV. Similarly, we under-explored perceptions of contraceptive requirements for women placed as part HIV cure trials, and these may have implications grounded in local socio-cultural contexts in Africa. Our results may not be generalizable to settings outside of Durban, South Africa; however, we reported findings with fidelity to the data collected. Additional socio-behavioral research is underway with the FRESH cohort in the context of the FRESH HIV cure-related interventional trial.

Conclusions

There is a pressing need to increase the representation of women in HIV cure-related research and to conduct trials in regions that bear the highest HIV burden. Early engagement of communities where HIV cure trials are planned may offer insights for resource allocation, the opportunity to communicate the value of ATIs and their associated challenges, acceptable partner protections, and disclosure support needs, and ultimately, contribute toward safer and more equitable enrollment in cure-related research. With HIV cure trials set to launch across Africa in the future, there is a critical need to better understand and respond to local community needs and preferences and to adopt this as standard practice prior to regional trial implementation.

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Authors' contributions

Conceptualization: K.Du., K.Do. Data Curation: K.Du., D.Mi. Project Administration: K.Du., K.Do. Data Collection (Focus Group Discussions): D.Mt.

Transcriptions and Translations: W.N. Clinical Liaisons: L.M., V.P. Formal Analysis and Investigation: K.Du., D.Mi., K.Do. Funding Acquisition: K.Du., K.Do. Supervision K.Du., K.Do. Writing – original draft preparation: K.Du. and K.Do. All authors reviewed and edited manuscript drafts including the final draft of the manuscript.

Disclosure statement

KD and TN provide advisory services to Gilead Sciences, Inc. All other authors declare that they have no competing interests.

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ORCID

Karine Dubé http://orcid.org/0000-0003-3458-1539

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